



Perspective

## Research with indigenous populations in Brazil: particularities and challenges

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Epidemiological studies that evaluate the health of Brazilian indigenous populations are scarce. Recently, the Australian Institute Lowitja, in partnership with the English magazine 'The Lancet', released a study analyzing the state of health and social status of indigenous and tribal peoples around the world [1]. In Brazil, a single national study was conducted in 2009, the First National Health and Nutrition Survey of indigenous peoples (*I Inquérito Nacional de Saúde e Nutrição dos povos indígenas*) [2]. Examples of ad hoc studies on cardiovascular risk factors in indigenous peoples have been published in recent decades [3, 4, 5-7, 8, 9, 10].

Studies on indigenous populations are important in developing specific responses and policies appropriate to these populations, as well as improving access to health services and stimulating the production of information on indigenous peoples within national health surveillance systems [11]. The scarcity of research with indigenous populations can be justified by a number of factors, such as bureaucratic procedures necessary for the approval of the research, execution costs, cultural and geographical barriers, as well as peculiarities related to indigenous populations.

In Brazil, research involving indigenous communities or individuals must meet the ethical and scientific requirements indicated in Resolution 466/2012 and Resolution 304/2000 of the National Health Council of the Ministry of Health [12,13]. The

first step is to have the documented agreement of the indigenous leaders of the community that is to be researched, which can be obtained through the respective indigenous organizations or local councils. After authorization from the community leaders, the process is initiated by following Resolution 466/2012 for the analysis and approval of the Ethics and Research Committee (ERC) of the institution where the researchers responsible for the research are linked, and, because it is a study of an indigenous population, it must be sent to the National Commission of Ethics in Research (*Comissão Nacional de Ética em Pesquisa - CONEP*).

After CONEP approval, the process should be sent to the Brazilian bodies responsible for indigenous attention, such as the National Indian Foundation (*Fundação Nacional do Índio - FUNAI*) and the Indigenous Special Sanitary District (*Distrito Sanitário Especial Indígena - DSEI*), the latter being linked to the Ministry of Health. FUNAI will send the research project to CNPq, to analyze its scientific merit, according to Normative Resolution-RN 009/1987 and Normative Instruction of FUNAI n° 001/PRESI/1995 [14,15]. In the referral of the process to FUNAI, in addition to the request for authorization to carry out the research, it should also request permission to access indigenous lands.

There are a number of documents required by FUNAI from the researchers involved in the research, to authorize entry into indigenous territory, specified in FUNAI Normative Instruction n° 001/PRESI/1995 [15]. The process of submitting the project to the ERC and to CONEP is carried out through the Plataforma Brasil website (<http://plataformabrasil.saude.gov.br>).

After approval of the research by those responsible, the indigenous person will only be considered a participant of the research after reading and signing of the Informed Consent Term (ICT). This document records the free and informed consent of the participant and/or their legal guardian, in written form, after reading and understanding all relevant information regarding the research, which must be written in clear, objective and easy to understand language, for the most complete clarification about the research in which they propose to participate [12]. When indigenous people do not speak or understand the Portuguese language, a person is required to perform the translation, such as a Community Health Agent for Indigenous People (*Agente Comunitário de Saúde Indígena-ACSI*). ACSIs are health professionals and members of health teams working in the indigenous context. In cases of non-literate indigenous people unable to sign the ICT, their fingerprint must be obtained on the ICT copies.

Following all these steps for authorization of the research is a process that can take a long time, so it is very important to plan ahead to achieve the final goal of the research. In addition, research with indigenous people is usually expensive, because they demand resources for housing, transportation, supplies, and equipment, and since most of the indigenous people live in communities away from large research centers the research requires funding from government development agencies.

In view of the above, it is possible to observe that the rights of indigenous peoples in Brazil, as regards the development of research on human beings, are well represented by the legislation that protects indigenous peoples as individual and collective participants in the research. These norms also recognize the right of indigenous peoples to participate in research or not, without prejudice to indigenous

peoples' right to full access and exercise of their rights.

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